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Recommendations

1. Support services to ensure all staff who deliver aged care receive mandatory, high quality training, particularly in relation to caring for patients with dementia and alternatives to restrictive practices.
2. More funding to build the capacity of the aged care workforce to deliver high quality care which should also include compulsory training in person-centred care.
3. Mandate appropriate ratio of skilled staff to consumers receiving aged care in residential facilities. This ratio must reflect the needs and demands of the residents (i.e. number of bedridden consumers).
4. Integrated approach to medication management process for older people accessing aged care services (residential and community settings) that combines dispensing, medication review and more education for care staff on medicines safety and quality use of medicines. This includes embedding pharmacists into residential aged care facilities.
5. Increase frequency of unannounced, randomised inspections conducted by accreditation bodies for aged care. This should:
 - be at least once in a year for all, with extra targeted inspection for at-risk providers, and
 - involve inspectors speaking with a higher percentage (at least 20%) of residents and families about the care they receive, and that people can speak with the team after the visit without the provider necessarily knowing they are going to have that conversation.

Accreditation should move away from compliance and sanctions to a focus on quality, safety and improvement.
6. Involve consumers in the assessor workforce which accredits community and residential aged care.
7. Assess multi-purpose services against one set of standards, the National Safety and Quality Health Services Standards Aged Care Module.
8. Investigate future accreditation practices. This would include an examination of the development and implementation of joint aged care and national safety and quality assessment surveys on the basis that this could potentially produce the following outcomes:
 - reduce duplication of effort,
 - promote efficient use of resources and staff time in the health organisations, and
 - enable a holistic assessment of services in one visit.
9. Urgently address the long waiting list for home care packages.
10. Review provision of residential aged care to ensure the increasing demand is met and waiting lists are reduced, including more funding.
11. Develop more effective channels between residential aged care facilities and external health care services.
12. Address the inadequacy of care provided to young people in aged care and the need for alternatives.
13. Strengthen and increase awareness of consumer protections to enable residents to exercise their rights in aged care. This includes increasing the funding for Advocacy organisations for older Australians through the Older Persons Advocacy Network.

Introduction

The Consumers Health Forum (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health care consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is consumer-centred care, with safety, quality and consumer participation key areas of focus¹.

With our population ageing, the quality and safety of aged care is a key area of focus for Australians. According to the Australian Institute of Health and Welfare, Australians aged 65 and over, represented 15% (3.8 million) of the total population in 2017². Over the coming decades, this proportion is expected to grow to 23% by 2066³. As a result, there will be a greater demand for aged care services, growing pressures on government budgets, and further pressures to increase the aged care workforce as our working age population decreases. In addition, the needs of older Australians requiring care will change driven by developments in technology, diverse preferences and expectations of care, and changing patterns of disease⁴. Understanding the reality of older people's lives is essential if their needs and expectations are to be met.

Previous reviews of the aged care system have concluded substantial reform is required. The Productivity Commission report, *Caring for Older Australians (2011)*, stated:

"The aged care system suffers key weaknesses. It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills⁴."

The reforms set out with the aim of improving aged care sustainability, quality and affordability while shifting towards a system driven by consumers. A review of the reforms in 2017 revealed progress had been made however further work was still required to provide people with greater choice and control over aged care services they receive.

CHF appreciates the opportunity to provide a submission to the Royal Commission into Aged Care Quality and Safety (Royal Commission). Our response to this public consultation has been informed by our wide experience with consumers including our previous submissions on this topic, the results of a survey to which 117 Australian health consumers responded and four telephone interviews. The survey and interviews conducted were in relation to different sections

¹ Consumers Health Forum of Australia. 2018-2022 Strategic Plan: <https://chf.org.au/2018-2022-strategic-plan>, accessed 19 June 2019.

² Australian Institute of Health and Welfare 2018, Older Australia at a glance, AIHW, <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians>, accessed 19 June 2019.

³ Australian Bureau of Statistics 2017, Population Projections, Australian 2017-2066, Cat. No. 322.0, <https://www.abs.gov.au/AUSSTATS/abs@.nsf/mf/3222.0>, accessed 19 June 2019.

⁴ Productivity Commission, *Caring for older Australians*, Report No. 53, 2011, Vol. 1.

of the Terms of Reference to gain insights into the views and lived experiences of consumers. A series of case studies have been developed from the telephone interviews and are attached as Appendix 1. A report detailing the key results from the survey is attached as Appendix 2.

Our submission in response to the public consultation of the Royal Commission covers the following key considerations:

- Workforce
- Medication management
- Aged care service accreditation
- Access to aged care services and health care, and
- Patient-centred aged care services.

Key Considerations

Workforce

Terms of Reference:

- b) How to best deliver aged care services to:
 - ii) the increasing number of Australians living with dementia having regard to the importance of dementia care for the future of aged care services.**
- j) The critical role of the aged care workforce in delivering high quality, safe, person-centred care, and the need for close partnerships with families, carers and others providing care and support.*

The aged care workforce is at the heart of improving the delivery of safe, high quality and patient-centred care to older Australians. Workforce and skill requirements will continue to evolve as the aged care sector grows, and the services provided change to meet the changing needs and increasing diversity of older Australians. The 2016 National Aged Care Workforce Census and Survey estimated 366, 027 aged care workers across residential (235, 764) home care and home support (130, 263), a 4% increase since 2012⁵. By 2050, the Productivity Commission estimates that each year, over 3.4 million Australians will be using aged care services. To meet these growing demands, the aged care workforce will need to grow to 980, 000⁵.

The delivery of safe and quality age care largely depends upon employing not only adequate numbers of workers to meet the demands of the aged care service (community and residential) but also people with the required skills. A recent report on Australia's future workforce states 'Today, the average worker is missing around 2 of the 18 critical skills that are advertised for a

⁵ Department of Health 2017, '2016 National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016, Commonwealth of Australia, <https://www.gen-agedcaredata.gov.au/www.aihwgen/media/Workforce/The-Aged-Care-Workforce-2016.pdf>, accessed 21 June 2019.

job⁶. Our recent consultations suggested skill shortage is prevalent in the aged care workforce. Many consumers raised concern that staff delivering aged care services did not have the appropriate skills to deliver high quality, safe and appropriate care, particularly in relation to caring for people with dementia. Painaustralia echoed these concerns of inadequate skills and training in their Submission to the Royal Commission and stated '*Aged care staff with day-to-day responsibilities for residents should have adequate knowledge and skills in pain assessment and management, including for people with dementia or other cognitive impairment*'⁷. Skill shortage, coupled with staff shortages, inappropriate staff to patient ratio, poor communication skills, and high staff turnover were the key concerns raised by consumers in both our survey and interviews. One consumer said:

"So understaff that it's dangerous for residents, bells go unanswered and time spent with them is rushed."

[Respondent #22, former worker in residential aged care]

While another consumer said:

"A positive workplace culture with a stable workforce will help to provide person-centred care"

[Respondent #110, carer and/or family member, residential aged care]

The Aged Care Quality Standards, Standard 7 clearly states "*the organisation has a workforce that is sufficient, and is skilled and qualified, to provide safe, respectful and quality care services*"⁸. Evidently, this is not the experience for many consumers. With staff and skill shortages in the aged care workforce, there is a risk that consumers feel they have no choice but to accept poor quality care.

As COTA highlights in a position paper⁹, mandated ratios alone are not enough to solve the current and future issues facing our aged care workforce. In addition, the current nature of training of aged care workers alone is not enough, that is, the mere existence of mandated training is not sufficient. Both residential and community aged care services should be supported to provide staff with training. The Aged Care Workforce Strategy¹⁰ highlighted a multifaceted approach required and identifies 14 strategic actions for Australia's current and future aged care workforce:

⁶ Deloitte Insights, 'The path to prosperity: Why the future of work is human', Building the Lucky Country #7.

⁷ Painaustralia 2019, 'pinaustralia: Royal Commission into Aged Care Safety and Quality', available online at <https://www.pinaustralia.org.au/static/uploads/files/royal-commission-into-aged-care-submission-from-pinaustralia-v3-wfhmcscbvdyq.pdf>

⁸ Aged Care Quality and Safety Commission 2019, 'Aged Care Quality Standards', Australian Government, available at: <https://www.agedcarequality.gov.au/sites/default/files/media/Aged%20Care%20Quality%20Standards.pdf>

⁹ COTA Australia 2018, 'Keep fixing Australia's aged care system...taking the next steps in tandem with the Royal Commission', Position Paper.

¹⁰ A Matter of Care Australia's Aged Care Workforce Strategy, Aged Care Workforce Strategy Taskforce, June 2018.

1. Creation of a social change campaign to reframe caring and promote the workforce
2. Voluntary industry code of practice
3. Reframe the qualification and skills framework – addressing current and future competencies and skills requirements
4. Defining new career pathways including accreditation
5. Developing cultures of feedback and continuous improvement
6. Establishing a new standard approach to workforce planning and skills mix modelling
7. Implementing new attraction and retention strategies for the workforce
8. Developing a revised workforce relations framework to better reflect the changing nature of work
9. Strengthening the interface between aged care and primary/acute care
10. Improved training and recruitment practices for the Australian Government aged care workforce
11. Establishing a remote accord
12. Establishing an Aged Care Centre for Growth and Translational Research
13. Current and future funding considerations, including staff remuneration, and
14. Transitioning the existing workforce to new standards.

While CHF support these strategic actions in principle, particularly 3, 5 &10 and recognise a multifaceted approach is required to build the capacity of the current and future aged care workforce, our recommendations focus on areas we believe should be prioritised.

Recommendations

1. Support services to ensure all staff who deliver aged care receive mandatory, high quality training, particularly in relation to caring for patients with dementia and alternatives to restrictive practices.
2. More funding to build the capacity of the aged care workforce to deliver high quality care which should also include compulsory training in person-centred care.
3. Mandate appropriate ratio of skilled staff to consumers receiving aged care in residential facilities. This ratio must reflect the needs and demands of the residents (i.e. number of bedridden consumers).

Medication Management

Terms of Reference:

- a) *The quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systematic failures, and any actions that should be taken in response.*
- i) *All aspects of the quality and safety of aged care services including but not limited to the following:*
 - iv) *medication management*

Evidence demonstrates medication safety is a significant problem for older Australians receiving aged care. A recent report from the Pharmaceutical Society of Australia on medication safety suggests up to 80% of residents in aged-care facilities, and 4 in 10 older Australians living in community are prescribed potentially inappropriate medicines, while over 90% have at least one medication-related problem¹¹. In addition, according to the latest data from the Aged Care Quality and Safety Commission, the most common type of complaints received are in relation to medication management in residential aged care¹². There are many issues with the current medication management processes for older Australians receiving aged care including; inappropriate use of psychotropic drugs, polypharmacy and access to well informed medication reviews and assistance, all of which were highlighted through our survey and interviews (Appendix 1 and 2).

Psychotropic drugs are often prescribed to control symptoms and assist with controlling difficult behaviour, leading to many consumers with dementia taking these drugs over extended periods. A recent study by Macquarie University¹³ examined over 10,000 residents from 60 residential aged care facilities in NSW and ACT and found one in three aged care residents is chemically restrained through antipsychotic and psychotropic drugs. It is evident from our recent consultations that this is a common experience and a major concern for many family members and carers of people, primarily in residential aged care and is often given to people without individual consultation or family consent. One survey respondent said:

"...My husband's wandering was treated with risperidone – a form of chemical constraint (without consent) – the contrary, my pleas to have him taken off were ignored – it paralysed him, and he died within months..."

[Respondent #45, carer and/or family member, residential aged care]

¹¹ Pharmaceutical Society of Australia 2019. Medicine Safety: Take Care. Canberra: PSA.

¹² Aged Care Quality and Safety Commission 2019, 'Sector Performance Data', Australian Government, available at: <https://www.agedcarequality.gov.au/sector-performance>

¹³ Kimberly E Lind, Magdalena Z Raban, Andrew Georgiou, Johanna I Westbrook. Duration of Antipsychotic Medication Use by Aged Care Facility Residents with Dementia Alzheimer's Disease and Associated Disorders.

CHF appreciates that people with dementia can have behavioural problems that may be difficult for aged care staff and carers to manage. Given the prevalence of these prescriptions, a major concern for CHF is the risk posed by adverse effects. People with dementia who are prescribed with psychotropic drugs have a higher risk of stroke, falls, hospitalisation and seizures leading to pre-mature death¹⁴. Not to mention, the inappropriate use of psychotropic drugs is not only a form of abuse, but a breach of the Aged Care Quality and Safety Standards. The amendment of the Quality of Care Principles 2014 announced earlier in April 2019 is a step in the right direction to help minimise the use of inappropriate chemical restraints¹⁵. However, rules and regulations alone are not enough.

When it comes to the management and reduction of inappropriate polypharmacy, there is a lack of routine and standard practices to support what should be expected practice. There has been progress in this area with the recent development of recommendations for a *National Strategic Action Plan to Reduce Inappropriate Polypharmacy*¹². This includes seven actions items targeting all sectors of the health care system including policy and regulatory environment of health, health care organisations, health care professionals, and consumers and the broader public, with the aim to reduce *'inappropriate polypharmacy and better health and quality of life for older Australians'*¹⁶. However, our recent consultations highlight more work is required. For those in residential aged care, some suggested *"medication is used to solve everything"*. One survey respondent said:

*"I also often discovered my father had been prescribed 'new' medications by the odd things that turned up on the pharmacy bill. Given I had full Guardianship of my father I had to inquire on multiple occasions as to what these medications were for, who prescribed them and why. I raised this issue multiple times and eventually made a complaint to the HCC about the practices which included the **administration of scheduled drugs that subdued him to make him more compliant.**"*

[Respondent #15, carer and/or family member - residential aged care]

This is just one of many examples captured through our recent consultations where consumers have been excluded from decision-making about medicines. We need to be working with patients, family members and carers to systematically capture their insights and measure their experience of care to help guide against inappropriate polypharmacy and identify where the breakdowns occur. After all, consumers are the one constant amid varied settings and clinicians. In addition, pharmacists have an important role to play with medication management. Consumers consider pharmacists to be up to date with medical advances and

¹⁴ Macfarlane, S & O'Connor, D 2016, 'Managing behavioural and psychological symptoms in dementia', Australian Prescriber: An Independent Review.

¹⁵ Wyatt, K 2019, 'Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019, Australian Government, available at: <https://www.legislation.gov.au/Details/F2019L00511>

¹⁶ Quality Use of Medicines to Optimise Ageing in Older Australians: Recommendations for a National Strategic Action Plan to Reduce Inappropriate Polypharmacy (2018). NHMRC Cognitive Decline Partnership Centre, University of Sydney, in Collaboration with the Australian Deprescribing Network and NPS MedicineWise. Sydney, NSW, Australia. ISBN: 978-0-6482658-6-3, Available from: <http://sydney.edu.au/medicine/cdpc/resources/quality-use-of-medicines.pdf>

think they could play an important role in the deprescribing process and effectively reduce medication burden or harm while improving the consumer's quality of life. Pharmacist education of other health professionals in deprescribing of medicines and awareness of prescribing habits is another important role that should be strengthened.

Access to well informed medication reviews and assistance have an important role to play for improving medication management for older Australians in both residential and community aged care settings. Yet our consultations suggest there is not a consistent approach to this. There were concerns raised about the frequency of medication reviews, with many people suggesting they did not happen enough. In addition, many people expressed frustration that they had to initiate a medication review to make it happen. One survey respondent said:

"The complexity of medications requires a lot more explanation than what is given..."

[Respondent #44, carer and/or family member – residential aged care]

On the other hand, one respondent had weekly reviews with their GP, while others had their medication reviewed by their pharmacist and managed using Webster Packs.

The solution: An integrated approach to medication management

Pharmacists have an important role to play to improve current medication management process and the recommendation made in the Review of Pharmacy Remuneration and Regulation report for pharmacy support for residential aged care facilities is very welcomed¹⁷. The University of Canberra and Goodwin Aged Care Services recently partnered to deliver a trial in the ACT where pharmacists were embedded into residential aged care facilities. The trial demonstrated improvements in quality use of medicines, as well as great collaboration and communication with the multidisciplinary team. The success of the program led to the federal government announcing \$3.7 million investment to embed pharmacists into residential aged care facilities across the ACT. CHF welcome the wider implementation of this approach, however, we agree with the Pharmaceutical Society of Australia that '*a national commitment is urgently needed to embed pharmacists in residential aged care facilities across the country*'¹⁸.

Recommendations

4. Integrated approach to medication management process for older people accessing aged care services (residential and community settings) that combines dispensing, medication review and more education for care staff on medicines safety and quality use of medicines. This includes embedding pharmacists into residential aged care facilities.

¹⁷ King, S, Watson, J & Scott, B 2018, 'Review of pharmacy remuneration and regulation: final report', Department of Health, available at: <https://apo.org.au/node/143826>

¹⁸ Pharmaceutical Society of Australia 2019, 'National commitment needed to embed pharmacists in residential aged care', available online: <https://www.psa.org.au/national-commitment-needed-to-embed-pharmacists-in-residential-aged-care/>

Aged Care Service Accreditation

Terms of Reference:

- d) *What the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe*

Consumers view accreditation systems as key to ensuring our healthcare system is and remains safe. An important component of safety and quality of aged care is the way people experience the services¹⁹. Measuring consumer experience offers the opportunity to identify gaps in aged care such as poor or unsafe practice and guide improvements in safety and quality. As part of the current accreditation process for residential aged care facilities, assessors are required to interview at least 10% of those living at the facility to gain insight into experiences of quality of care and services. These experiences are then collated into a Consumer Experience Report²⁰. According to the Aged Care Quality and Safety Commission, 'Consumer Experience Reports are aimed at promoting consumer choice by capturing the consumer experience of the quality of care and services in aged care²⁰'. However, recent consultation suggests this level of consumer input is inadequate. One survey respondent said:

*"Make accreditation more than just a tick the boxes exercise **without adequate input from residents and families**"*

[Respondent #5, Nurse Manager in Residential Aged Care]

While CHF strongly support this process, we do not believe 10% provides an adequate representation of consumer experience at a residential aged care facility. CHF also agree that accreditation needs to move away from a 'tick the box exercise'. The focus needs to be on quality, safety and improvement rather than on compliance and sanctions. It is important to note that CHF strongly believe that all standards need to be thoroughly monitored, and serious consequences applied to aged care organisations that fail to address any identified deficiencies in a suitable timeframe, a position the Health Care Consumers Association of the ACT also highlighted in their submission to the Royal Commission. However, the accreditation process should be driven by a culture of continuous quality improvement, supporting aged care services (both community and residential) to improve safety and quality of care and services.

Another problematic component of the current accreditation process is aged care providers know when to expect accreditation bodies to conduct a site inspection. While the exact date of the inspection is no longer announced since the Australian Aged Care Quality Agency Act 2013²¹ was amended in 2018, aged care providers can expect the 'unannounced' site audit between

¹⁹ Borgardt, I, Groom, C & Taylor K 2007, 'Improving Quality and Safety: Progress in Implementing Clinical Governance in Primary Care: Key Questions for PCT Boards', National Audit Office, https://www.nao.org.uk/wp-content/uploads/2007/01/0607100_key.pdf

²⁰ Aged Care Quality and Safety Commission, 'Consumer Experience Reports', Australian Government, available at: <https://www.agedcarequality.gov.au/consumers/consumer-experience-reports>

the time they apply for re-accreditation and the expiry date of their current accreditation²¹. This was a concern raised by many consumers in our recent consultation. One survey respondent said:

“The trouble with the Accreditation Scheme is that the aged care facilities know that an inspection is looming, and they prepare near the date for it to happen to ensure they retain their accreditation.”

[Respondent #10, carer and/or family member – residential aged care facility]

This may prevent accreditation teams from detecting the service providers ‘everyday performance against the Accreditation Standards’²² – the very intent of introducing ‘unannounced’ site audits. CHF recommend increasing the frequency of unannounced, randomised inspections conducted by accreditation bodies for aged care.

CHF also strongly believe consumers can be agents of change and play an important role in helping that change have a real impact. This means:

- consumer perspectives being integral to every aspect of the accreditation process: setting standards, assessing quality, managing risks and operating with transparency and accountability to the community and the taxpayer,
- consumer involvement in university training, continuous professional development and working alongside a broad range of stakeholders on assessment teams and panels, and
- having accreditation requirements that include the need to demonstrate how consumers are involved in this training.

We strongly recommend that consumers are involved in assessment panels which accredits residential aged care facilities. This should consist of at least two consumers, and they should be trained and be prepared to be full members of the audit team, not tokenistic consumers who are interested in just the consumer experience.

In addition, the current accreditation system involves multiple assessments to different standards causing regulatory burden, inefficiencies, and higher costs. As the Australian Council on Healthcare Standards states in their submission:

“The current system separates out quality and safety, policy and funding for aged care and health care under different ministerial portfolios. Policy needs to focus on looking after people throughout their life journey. Consideration needs to be given as to whether it helps or potentially compromises health outcomes by having separate accreditation regimes. Care issues of safety and quality (e.g. infections, UTIs, falls, pressure injuries) are central to both aged

²¹ Aged Care Quality and Safety Commission 2019, ‘Accreditation and Re-accreditation’, Australian Government, available at: <https://www.agedcarequality.gov.au/providers/assessment-processes/accreditation-and-re-accreditation#about> accreditation and reaccreditation

²² Australian Government 2019, ‘Current quality assessment arrangement, including unannounced re-accreditation audits’, Department of Health, available at: <https://agedcare.health.gov.au/quality/current-quality-assessment-arrangements-including-unannounced-re-accreditation-audits>

care services and hospital care, and are included in the National Safety and Quality Health Service (NSQHS) Standards²³.”

Replacing the current system to one that uses one set of health care assessment standards has the potential to increase efficiencies, reduce regulatory burden and potentially reduce costs. At the very least, there should be some common standards across aged and health care services in relation to clinical service delivery to older Australians. CHF recommends an investigation into future accreditation practices, including an examination into the development and implementation of joint aged care and national safety and quality assessment surveys.

Recommendations

5. Increase frequency of unannounced, randomised inspections conducted by accreditation bodies for aged care. This should:
 - be at least once in a year for all, with extra targeted inspections for at-risk providers.
 - involve inspectors speaking with a higher percentage (at least 20%) of residents and families about the care they receive, and that people can speak with the team after the visit without the provider necessarily knowing they are going to have that conversation.Accreditation should move away from compliance and sanctions to a focus on quality, safety and improvement.
6. Involve consumers in the assessor workforce which accredits community and residential aged care.
7. Assess multi-purpose services against one set of standards, the National Safety and Quality Health Services Standards Aged Care Module.
8. Investigate future accreditation practices. This would include an examination into the development and implementation, including the challenges and benefits of joint aged care and national safety and quality assessment surveys on the basis that this could potentially produce the following outcomes:
 - reduce duplication of effort,
 - promote efficient use of resources and staff time in the health organisations, and
 - enable a holistic assessment of services in one visit.

²³ The Australian Council on Healthcare Standards (ACHS) 2019, ACHS Submission to the Royal Commission into Aged Care Quality and Safety.

Access to Aged Care Services

Terms of Reference:

- b) *How to best deliver aged care services to:*
 - i) *people with disabilities residing in aged care facilities, including younger people.*
- K) *The wide diversity of older Australians and the barriers they face in accessing and receiving high quality aged care services. This should take into account the increasing incidence of chronic and complex conditions.*

Access to Aged Care Services

Our aged care system is not keeping up with Australia's ageing population. The latest report published by the Government shows that 93, 331 older Australians were in a home care packages. However, as at 31 March 2019, 75, 739 people remained in the national queue²⁴. The report further shows older Australians are waiting too long to receive the care they need. For example, the latest estimated wait time for a person assessed at a Level 4 Package (the highest level of care recognised) is at least two years. This estimate reflects the time from the initial day of assessment, to the day the person receives the package level they were assessed. During the 2-year waiting period, people have the option to receive a lower level package, however even then, they can expect to wait 12 months before receiving any care at all. Some people pass away before they receive the care they need. These are not just numbers in a report, it is the reality for many older Australians. One survey respondent said:

"My brother-in-law was given a stage [level] 4 packages; he was on a 2 year wait list. He died 4 months after he got the package allocation, so he died 22 months before they were going to give him the care services."

[Respondent #66, carer and/or family member - residential aged care]

Many consumers would prefer to remain living in their own home as they age, however with the lack of availability of Home Care Packages, consumers are being left with no choice but to move into residential aged care. According to a recent COTA Australia report, this occurs 'even if residential care is not necessarily the most appropriate or best option'²⁵.

²⁴ Department of Health, 'Home Care Packages Program – Data Report 3rd Quarter 2018-2019', Australia 2019, accessed 6 September 2019, https://www.gen-agedcaredata.gov.au/www.aihwgen/media/Home_care_report/HCPP-Data-Report-2018-19-3rd-Quarter-March-2019.pdf

²⁵ C.Irlam, Project Report: Measuring Quality and Consumer Choice in Aged Care, Australia, COTA Australia, 2018, p.144.

One survey respondent said:

“Can’t get basic services, if you make it to a wait list, they are long and if you don’t get in early you end up getting to a point where your option is nursing home.”

[Respondent #9, carer and/or family member - community aged care]

The long waiting list for older Australians to receive Home Care Packages must be urgently addressed to ensure people receive the right care, in a timely manner, where they choose. With the current shortages, consumers are left with limited or no choice but to accept what they are offered (both in residential or community settings), and many feel less able to complain or demand better care. CHF strongly believe there is an urgent need to address the long waiting list for home care packages and review the provision of residential aged care to ensure the increasing demand is met.

In addition, there is a need to address the inadequacy of care provided to young people in aged care. Residential aged care is often the last resort for younger people with a disability who are unable to secure appropriate housing or supports. However, aged care services are designed and equipped to meet the needs of older Australians, not younger people with disability²⁶. This issue was highlighted in our recent survey where one respondent said:

“My father entered a facility at the age of 60; he was not the youngest there was a 40-year-old next to him. These facilities have considerable difficulty in managing these residents because of their age they require a different style of interaction and activity.”

[Respondent #15, care and/or family member – residential aged care]

The *Younger People in Residential Aged Care – Action Plan*²⁶ is a step in the right direction, however more support is required to address the inadequacy of care provided to young people in aged care immediately.

Access to Health Services

With many older consumers living with multiple complex health care needs typically including one or more chronic conditions, depression and neurodegenerative conditions like dementia, the adequacy of access to healthcare services in aged care settings is essential. Consumers in residential aged care are largely dependent on other people for health needs, including in seeking health services.

Older consumers are often unable to visit their own doctor. Increasingly, they rely on deputising doctors to provide primary care in their own environment or their aged care facility²⁷. CHF welcomed the Productivity Commission’s proposal to develop more effective channels between

²⁶ Australian Government 2019, ‘Younger People in Residential Aged Care – Action Plan’, Department of Social Services, available at: https://www.dss.gov.au/sites/default/files/documents/03_2019/younger-people-aged-care-infographic.pdf

²⁷ Consumers Health Forum of Australia 2013, CHF Submission to the Senate Community Affairs Committee Inquiry into the Living Longer Living Better Aged Care Bills 2013, CHF: Canberra.

residential aged care facilities and external health care services⁴. However, more work is required. Our consultations showed 17% of survey respondents felt they (or someone they knew) **did not** have access to a general practitioner or a specialist of their choice when required. While another 26% of survey respondents felt it 'varied' and felt that while they had access to a GP that regularly visited the residential aged care facility, this was not their GP of choice. One person stated:

"In rural communities it is impossible to have choice and so older people have to adapt to getting on with someone they may not trust or like"

[Respondent #106, carer and/or family member - residential aged care]

This left people feeling 'vulnerable and unable to make personal choices' and 'impotent and depressed'. In comparison, those who said they (or someone they knew) **did** have access to a general practitioner or a specialist of their choice when required felt 'safe', with one person stating:

"Very satisfied that my family member was being looked after in accordance with her wishes and receiving high quality and respectful care".

[Respondent #4, family member - residential aged care]

CHF strongly believes more work is required to develop more effective channels between residential aged care facilities and external health care services to provide consumers with choice and control. Integrated care models, such as the ICP OP 10 Step Framework to Integrated Care for Older Persons²⁸ offers a step in the right direction. The Framework offers flexibility, recognising the need to tailor the approach to meet local needs. The initial evidence also shows utility among clinicians and managers. Such an approach has the potential to bridge gaps associated with systematic change.

Recommendation:

9. Urgently address the long waiting list for home care packages.
10. Review provision of residential aged care to ensure the increasing demand is met and waiting lists are reduced, including more funding.
11. Develop more effective channels between residential aged care facilities and external health care services.
12. Address the inadequacy of care provided to young people in aged care and the need for alternatives.

²⁸ Harnett, P.J, Kennelly, S & Williams, P 2019, 'A 10 Step Framework to Implement Integrated Care for Older Persons', *Ageing International – Springer*, available at: <https://doi.org/10.1007/s12126-019-09349-7>

Person-centred aged care services

Terms of Reference:

- e) *How to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters.*
- i) *All aspects of the quality and safety of aged care services, including but not limited to the following:*
 - i) *Dignity*
 - ii) *Choice and control*

CHF recognise there are varying definitions of patient-centred care however for the purpose of this submission, CHF refer to patient-centred care as:

“health care that is respectful of, and responsive to, the preferences, needs and values of the patients and consumers”²⁹.

CHF is pleased that person-centred care forms an integral part of the Charter of Aged Care Rights³⁰, and the Aged Care Quality and Safety Standards³¹. However, unfortunately this long overdue Royal Commission is an indication that older Australians are not always the centre of the care they receive. Our survey and interviews only further highlight this reality. For example, some survey respondents highlighted individual needs were often not met, or even considered. This included the needs of carers and/or family members. In addition, people at residential aged care facilities experienced limited social interaction and stimulation. One survey respondent said:

“They are often given inappropriate food that they cannot swallow – programs that they cannot participate in and treated as though they are problematic when they do not conform to expectations”

[Respondent #45, carer and/or family member - residential aged care]

This was a shared concern for many respondents:

“Some staff...believe residents have to fit in with the institutional needs rather than the personal needs of the residents living in their home”

[Respondent #106, carer and/or family - residential aged care]

Patient-centred care cannot be simply added onto usual care but rather takes significant cultural and organisational change. The Australian Commission on Safety and Quality in Health

²⁹ Australian Commission on Safety and Quality in Healthcare (2011), ‘Patient-centred care: Improving quality and safety through partnerships with patients and consumers’, ACSQHC, Sydney, p7.

³⁰ Aged Care Quality and Safety Commission (2019), Charter of Rights, available at: <https://agedcare.health.gov.au/quality/single-charter-of-aged-care-rights>

³¹ Aged Care Quality and Safety 2018, Guidance and Resources for Providers to support the Aged Care Quality Standards.

Care describe seven key attributes of high-performing person-centred healthcare organisations including:

- Comprehensive care delivery
- Purpose, strategy and leadership
- People, capability and culture
- Governance
- Partnerships
- Technology and built environment, and
- Measurement³².

In our survey, we asked consumers how can the provider, or Australia generally, better ensure aged care services are patient centred. Many consumers highlighted the need for consumers to be empowered to exercise their rights. One respondent said:

"Clients and community also need to feel that they can challenge systems, and ask questions, that this is their right - they don't have to be powerless."

[Respondent #115, carer and/or family member – community aged care service]

While another respondent said:

"By providing the means for patients to express and discuss their concerns and receive a considered response."

[Respondent #40, carer and/or family member – community aged care service]

Furthermore, our recent consultations highlighted the need for increased access to consumer advocates in aged care. The Older Persons Advocacy Network share a similar view and stated in their contribution to the Terms of Reference for the Royal Commission, *'the need to provide recipients and their representatives improved access to an advocate of their choice including independent advocacy and external complaints mechanisms'*³³. Our survey (Appendix 2) found that many consumers felt 'fortunate' they were able to advocate on behalf of their family member receiving aged care services (both community and residential). Furthermore, the consumer case studies (Appendix 1) illustrate how the care some people were receiving may have been drastically different, or not provided at all, had family members been unable to advocate of their behalf. CHF strongly believe there is a need to strengthen and increase awareness of consumer protections to enable residents to exercise their rights in aged care, including an increase in the funding for advocacy organisations for older Australians.

³² Australian Commission on Safety and Quality in Health Care. Review of the key attributes of high-performing person-centred healthcare organisations. Sydney: ACSQHC; 2018.

³³ Older Persons Advocacy Network (OPAN) 2018, 'Response to request for input to the Terms of Reference for Royal Commission into Aged Care Quality and Safety', OPAN, available at: <https://www.opan.com.au/wp-content/uploads/2018/10/OPAN-Input-into-Royal-Commisison-Aged-Care-Terms-of-Reference.pdf>

Recommendations

13. Strengthen and increase awareness of consumer protections to enable residents to exercise their rights in aged care. This include increasing the funding for Advocacy Organisations for older Australians such as the Older Persons Advocacy Network.

Conclusion

Overall, our submission covers key considerations on workforce, medication management, aged care service accreditation, access to aged care and health care services, and the need for patient-centred aged care services.

- Skill shortage, coupled with staff shortages, inappropriate staff to patient ratio, poor communication skills, and high staff turnover are crippling the current aged care workforce and preventing older Australians from receiving safe, high quality and patient-centred care.
- There are many issues with the current medication management processes for older Australians receiving aged care including; inappropriate use of psychotropic drugs, polypharmacy and access to well informed medication reviews and assistance.
- Accreditation needs to move away from a 'tick the box exercise' and focus on quality, safety and improvement rather than on compliance and sanctions.
- The waiting list for a person assessed at a Level 4 Home Care Package is at least two years and some people pass away before they receive the care they need.
- This long overdue Royal Commission is an indication that older Australians are not always the centre of the care they receive. Individual needs are often not met, or even considered and limited social interaction and stimulation provided to older Australians in aged care.

There is no question that our aged care system requires urgent attention. CHF are concerned the recent announcement of a 6-month extension to the Royal Commission will delay the Government taking action to address the serious problems in our aged care system. We support the Australian Medical Association and the Australian Nursing and Midwifery Federation call on the Federal Government to act now. Older Australians should not have to wait another 12-months to receive safe, quality and patient-centred care. The Commission should include reasonable timeframes, in consultation with relevant organisations, for all its recommendations.

Appendix 1: Consumer Case Studies

Leah's Story

The name has been changed but the experiences are real. This case study focuses on the experience of a woman who was highly engaged and involved in the care for her late father who lived in two different residential aged care facilities over seven years. This story is told from the perspective of the woman.

Leah's father lived in the first residential aged care facility for 15 months. During this time, Leah felt concerned about the quality of care her father was receiving and often felt she was not listened to or treated with respect by staff. For example, Leah would often visit her father to find him covered in bruises. It was only when she asked staff what had happened that she would be advised her father had fallen over. This happened on multiple occasions, leaving Leah feeling increasingly concerned for her father's wellbeing and frustrated by the lack of communication from staff. In addition, Leah was particularly concerned that evening staff were treating her father too roughly, and noticed he constantly had skin tears that were not cared for properly which would lead to infection. For these reasons, Leah felt it was important to transfer her father to a different residential aged care facility to ensure he was receiving safe and quality care.

*"My father was constantly having skin tears which became infected.
The wound management was sub-optimal"*

Leah felt lucky to have found out about another facility nearby through a nurse she had befriended. The nurse had her mother in the same facility as Leah's father at the time and was moving her mother to one where she worked and knew the quality of care was significantly better. Knowing this, Leah felt confident that transferring her father to the same facility was the best option. Leah often wonders how she would have found out which residential aged care facilities truly provided quality care had not befriended this nurse.

"Not easy I would say but I did it with great determination and insight because after a year and a half at the first place it became clear to me that things were bad, and they needed to change."

At the time, Leah's father was aged 94 and had dementia, adding stress to an already difficult transition from one residential aged care facility to another. To help ease the transition, Leah told her father a cover story about why they were moving. Unfortunately, staff at the residential aged care facility did not help Leah during this transition and cleared out her father's room before he had left the facility, causing him to feel extremely anxious and confused. Leah felt the staff could have been more understanding of her father's situation and assisted in any way they could to make the transition as stress free as possible.

At both residential aged care facilities, Leah felt she was involved in creating and reviewing her father's care and service plan and felt it reflected what was important for her and her father. However, Leah found that while the plans appeared good on paper, implementation was a key issue. For example, in the first residential aged care facility, Leah would have meetings with key staff members and service providers and leave feeling confident and full of hope. Unfortunately,

the facility was so understaffed that often services would not be delivered to her father as planned.

“I would walk away full of hope but eventually things sort of fell apart. I mean the fact was, there were not enough staff ever on the ground”

One thing that was really important to Leah was staying involved and engaged with her loved ones in residential aged care facilities. Leah felt there was much to observe and advocate for on behalf of her father, even at the second facility which she felt provided better quality care. For example, Leah felt that her father would not have seen health professionals such as dentists, physiotherapists or podiatrist in a timely manner had she not initiated and arranged appointments for him.

“Nothing would have happened if I didn’t initiate things...I initiated everything”

Leah felt lucky that her father’s long-term GP was located nearby the second residential aged care facility, making it easier to take him to appointments or for the GP to come to the residential aged care facility. Leah felt comforted knowing that her father was able to continue seeing his regular GP, one that they both knew and trusted. This was particularly important as her father reached the end of his life. The GP worked closely with both Leah and her father to ensure he was comfortable, and his wishes were respected during this difficult time.

“He was in his own room, in this lovely little cottage and all his favourite staff were around him, so it was very peaceful”

From Leah’s perspective, staffing was one of the most noticeable differences between the first and second residential aged care facility. For example, the staff at the second facility were more stable compared to the first facility which heavily relied on agency staff. This consistency provided comfort to both Leah and her father as they were able to get to know and develop a rapport with the staff. Friends and family who visited Leah’s father also noticed the difference this made and were impressed that when they showed up and asked to see him, staff would know exactly who he was. Leah considered this to be one of the most important aspects of her father’s care and gave her confidence, particularly when she was unable to visit, that her father was being well looked after.

“You really need to feel confident about it, that there is some loving, caring, competent person on duty, in the evenings especially, who is going to be kind to your loved one”

Another noticeable difference between the first and second residential aged care facility was level of staff experience and training, particularly in relation to caring for people with dementia. Leah recalls her father would experience delusions where he would believe he was back at his own house, walk around turning off all the lights, TV and telling other residents it was time to go for bed. Staff at the first residential aged care facility would often handle the situation by

turning the lights and TV back on. The situation would often escalate as Leah's father would simply turn the lights and TV back on. When this happened at the second aged care facility, one of the nurses would demonstrate to other staff members the best way to respond and avoid the situation escalating. Leah believes all staff should be trained in how to handle such situations.

"This is the sort of, specific training in handling patients with dementia that needs to be kind of universal in aged care facilities because so many of the residents...may be suffering some kind of cognitive impairment"

Over the years, Leah became increasingly aware of how lonely many of the other residents were at the aged care facilities. Some rarely, if ever, had visitors. When Leah visited her father, she would also try to get to know other residents and would often sit around tables together to enjoy a brief chat. Staff members would often tell Leah that they wished they had more time to spend with the residents, even just for a cup of tea and biscuit.

"It often doesn't take much you know because many of those residents are so starved for attention and time, so often even just a quick hello, sit down, can make all the difference in the quality of their day"

Overall, Leah felt there were both positive and negative aspects of her experience during the time her father was living in residential aged care. The number of staff available and their level of skill, particularly in relation to caring for people with dementia, was one of the key factors that Leah felt influenced the quality of care her father received. Leah strongly believes that had there been more staff at the first aged care facility, her father's care plan would have been implemented as planned, improving the quality of care he received. One aspect of the care that really stood out as exceptional was the way the nurse interacted with her father when he was experiencing delusions and turned a potentially distressing event into a positive one.

Rebecca's Story

The name has been changed but the experiences are real. This case study focuses on the experience of a woman whose late husband lived in a rural residential aged care facility for 12 months. This story is told from the perspective of the woman.

Rebecca was living in Brisbane at the time she was trying to find an appropriate residential aged care facility for her husband. Rebecca, still working at the time, found it very difficult to find a high care bed appropriate for her husband's needs. With limited availability in Brisbane, Rebecca explored other options in surrounding rural towns where she found it was easier to find a place appropriate for her husband. Rebecca decided to move to a retirement place in a rural town, an hour and a half west of Brisbane, near to where she had found a residential aged care facility for her husband. This move ultimately cost Rebecca her job in Brisbane.

Upon initial assessment, Rebecca's husband was assessed as high care, however as no high care beds were available, he was instead moved into a shared low care bedroom. Rebecca felt there were some positive aspects to this. For example, at the time, her husband was still quite mobile and being in low care gave him more freedom than he would have had in high care. However, as a result of the minimal supervision in low care, her husband could easily access alcohol at the local shops. Rebecca felt concerned that this would be detrimental to her husband's health, particularly as alcoholism had been a struggle in the past. Rebecca voiced her concerns and it was noted in her husband's care plan that he was not to have access to alcohol. Despite this, no action was taken by the residential aged care facility to prevent her husband accessing alcohol.

"In no way, shape or form did they accept any responsibility for allowing him to have access to alcohol...I would get a phone call to say he's been on the drink again"

Over the 12 months Rebecca's husband lived in the residential aged care facility, no high care beds became available. As a result, her husband remained in a shared low care bedroom. During this time, many people came and went, and staff would not always knock before they came in. Rebecca felt this was invasive of her husband's privacy.

Communication was important to Rebecca as both a wife and carer to her husband. There were some instances Rebecca felt staff communicated very well with her. For example, the physiotherapist and activities coordinator at the residential aged care facility both introduced themselves to Rebecca when they first met and explained what they were doing for her husband. This left Rebecca feeling well informed and involved in the care her husband was receiving as well as the activities he was involved in.

However often, Rebecca felt staff at the residential aged care facility did not communicate effectively with her, leaving her feeling excluded. Rebecca would visit her husband as often as possible, however commuting back and forth to Brisbane where she worked during the week, and caring for her son who had a disability, often meant Rebecca was only able to visit on weekends. As a result, Rebecca rarely had the opportunity to see the director of care or administrator of the residential aged care facility. Instead, Rebecca often interacted with weekend staff who were unable to provide the latest information. Rebecca felt communication could have been improved by simply calling her or sending an email to keep her informed.

Poor communication also meant Rebecca was often not involved in making decisions about her husband's care despite being recognised as statutory health attorney. For example, staff at the residential aged care facility would ask Rebecca's son to make decisions instead of consulting her. This included planning outings without Rebecca knowing until after the event, using the money she had put into the trust. Rebecca felt this was very inappropriate and that staff never accepted her right as statutory health attorney and financial administrator.

"They would ask him about things to make decisions which I thought was quite inappropriate...he was obviously the visible one during 9 to 5, Monday to Friday type shift."

Lack of communication from staff at the residential aged care facility also resulted in Rebecca losing precious time with her husband shortly before he passed away. It was over the Christmas break and Rebecca had booked a farm stay a couple hours' drive away where she, her husband and son with a disability could all spend quality time with other family members staying at the same rural accommodation. Upon returning to the residential aged care facility, everything appeared normal and staff settled her husband back into his room. Rebecca was on leave for a couple of weeks and was hoping to spend some more time with her husband, however the next day after returning from the farm stay, staff from the residential aged care facility phoned Rebecca to advise that there had been an outbreak of Norovirus at the facility. Rebecca had asked the staff to advise when it was all clear to come in however, they never did.

"Nobody had bothered to communicate with me that all was clear and that I was free to visit"

The next phone call Rebecca received from staff at the residential aged care facility was a few days later to advise that her husband was in hospital. Unable to find out much more, Rebecca rushed to hospital only to find her husband sitting up, laughing and joking. Rebecca, confused about what had happened, tried to find out more from hospital staff. Rebecca was shocked to find out that hospital staff were unaware that there had been an outbreak of Norovirus at the facility and was told her husband was just in for a check, that everything was fine, he was in no danger, and to go home to rest. Unfortunately, at 7am the next day, Rebecca received a devastating call from the hospital with the news her husband had passed away. During this time, Rebecca received very little information from either the residential aged care or hospital staff, depriving her the opportunity of spending precious times with her husband in his final days.

"Staff didn't take appropriate action, nor did they appropriately advise me so that I could have made some decision...the only communication I got from the facility was basically to say, 'you've got to pay money, you've got to move the things out of his room as soon as possible'"

Overall, during the time her husband lived in residential aged care, Rebecca felt she was often excluded. Staff rarely communicated important information to her or involved her in the decision-making process for her husband's care. Ultimately, poor communication resulted in

Rebecca missing out on precious time with her husband before he suddenly passed away in hospital.

Kate's Story

The name has been changed but the experiences are real. This case study focuses on the experience of a woman who was closely involved in the care for her late mum who lived in residential aged care for 2 years. This story is told from Kate's perspective.

In 2016, Kate's mum and dad moved into a residential aged care facility in a regional area of NSW close to Kate's sister. They both lived here together until Kate's mum passed away in 2018. Kate and her sister were both closely involved in the care for their parents and had legal guardianship.

Communication was a key issue during the time Kate's parents were in residential aged care. With advanced dementia, Kate's mum was unable to communicate her needs effectively, while her dad's short-term memory problems meant he couldn't provide reliable information.

"Unless you're actually going into a place regularly, you're very reliant on the organisation providing the care to give you clear information. And it wasn't something that we always felt was good."

One aspect that Kate found particularly difficult was that carers, that is the people who are on the frontline providing day-to-day care were not allowed to discuss any medical related issues directly with her. All medical related information had to go through the registered nurse working at the residential aged care facility. With only one registered nurse normally on duty at any given time, Kate felt they did not have the opportunity to get to know residents the same way the carers did. For example, Kate's mum was quite an anxious person and when she became agitated, Kate felt a registered nurse who did not know her well could interpret that behavior as pain whereas a carer who knew her mum well could recognise that her mum was just stressed.

With carers unable to communicate medical related issues, Kate felt it was difficult to understand what was going on. There were times when the registered nurse would call Kate to advise that her mum required medication for pain management. Without the registered nurse knowing her mum's typical behavior, Kate felt she couldn't trust this advice until she was able to visit her mum in person or speak to one of the carers who knew her mum well.

"Given the ratios between carers and RN's...there is no way that an RN is going to get to know an individual, so I think there needs to be some provision for carers to have a bit of a voice and be able to communicate with family."

This happened around the time Kate's mum had broken her hip after having a fall. Her mum was taken to hospital and had surgery. One week after Kate's mum had returned to the residential aged care facility, the registered nurse phoned to advise that her mum had been agitated and in pain since returning from hospital. The registered nurse was seeking consent to give her mum a pain patch, with the option to also give her Endone if required. Kate felt she had

no reason to question this at the time and provided consent for her mum to receive the pain medication. Two weeks later, Kate visited to see how her mum's care had changed only to find her mum dropping off to sleep during the day when she normally would have been quite 'with it'. In addition, one of the primary carers advised Kate she had expressed concern to the doctor about the effect Endone had on her mum and that she had been struggling to get her eating or drinking.

"Mum was extremely drowsy, and she was falling asleep every minute when I visited her. She would go from being lucid for a short time, making eye contact, going off with the fairies and falling asleep."

Kate had arranged two physiotherapists, one private and one in-house, to help her mum get up and walking again following hip surgery. Kate felt this was important as her mum was very active prior to her injury. While Kate was visiting, she met with both physiotherapists to see if they thought her mum was experiencing pain when walking. Both advised Kate that her mum didn't appear to be in any pain. Knowing this information from both physio's and her mum's regular carer, Kate met with her mum's GP and requested for the pain medication to be reduced. The doctor lowered the dose, and after a couple weeks, discontinued the pain patch and put Kate's mum on Panadol several times a day.

Kate continued to communicate with both physiotherapists to make sure her mum was not experiencing any pain and to see if she had become less agitated. Kate also took the opportunity to check in with her mum's regular carer when the carer phoned regarding another issue. To Kate's relief, her mum's level of awareness had improved, making it easier for the carer to give her food and fluid and interact.

"It was good because she was just a bit more with it and able to interact with my dad a bit more...we just wanted to give them quality time together"

Several weeks passed when Kate received a phone call from the residential aged care facility to advise that her mum had fallen out of bed but was ok. Another 10 days passed, and Kate's sister received a phone call from a registered nurse to discuss the option of giving their Mum some 'background' pain relief during things like personal care. She wasn't sure why this was needed out of the blue and Kate and her sister spent several days trying to get to the bottom of the request. From what they could determine their Mum had been experiencing acute pain during the week after the fall but the requests by one her carers that she needed pain relief were not addressed. By the time the option for 'background pain relief' was suggested by the RN their Mum's need for additional pain relief had largely passed.

"When my sister was discussing the issue with the RN, she discovered we were thought of as the family that did not want pain"

relief for their mother when actually we said we wanted it when it was appropriate. I believe this may have come about because I had earlier queried the on-going use of the pain patch”

Kate felt frustrated and upset that her mum had been experiencing pain unnecessarily. Kate felt these communication issues could have been easily avoided if carers were allowed to communicate medical related issues directly with the family, even if this was only limited to communicating very basic information. For example, had the carer been able to let the family know directly that their mum was experiencing pain when they were providing personal care, and that this had been reported to the registered nurse, Kate feels she would have had the opportunity to follow up with the registered nurse earlier and ensure her mum was receiving appropriate pain management medication in a timely manner.

There were other aspects of her mum’s care that Kate felt could have been improved. For example, after her mum’s hip surgery the residential aged care facility was quick to tell Kate that they did not have the capacity to rehabilitate her mum. Knowing how active her mum was before her injury, Kate knew it would be good not only for her mum’s physical health, but also her mental wellbeing to have the opportunity to stand up and walk again. Kate’s sister ended up having a meeting with the care manager and during that she was made aware that the aged care facility would consider providing physiotherapy. Kate pushed for this to occur and in-house physio was provided. In addition, Kate and her sister arranged a private physiotherapist to see their mum. Kate was surprised not all residents were given the opportunity to receive therapy to help keep them functioning physically and felt this was something that should be offered to all residents and regardless of their condition or stage of life. Kate felt that it was lucky that both her and her sister were able to advocate on behalf of their mum to ensure she had the opportunity to remain active and rehabilitate to some degree however was saddened to think some residents would simply go without.

“I was just fortunate to have that knowledge but if you don’t have that knowledge or have people that can help you or if you are a resident in a home that doesn’t have an advocate, then you are really at the mercy of people that might not have your best interests at heart.”

Another key issue was restraint. After Kate’s mum broke her hip, she spent time in bed recovering before eventually moving to a geri chair. The geri chair had a tray table fixed to the front to prevent her from standing up and a foot-plate on which her feet rested which would make it unsafe for her to stand up should she have the chance to. She would sit in the geri chair throughout the day. With advanced dementia and at high risk of experiencing another fall, the care manager advised Kate’s sister this was the best option to ensure her mum’s safety but there was no provision in her mum’s care for restraint-free time. Kate’s mum tried to get out multiple times when the tray table had been removed, suggesting to Kate that her mum still had a strong desire to stand up and move around. To give Kate’s mum the opportunity to sit more freely, like in a normal chair the carer would occasionally remove the tray table connected to the front of the chair. With other residents to care for, the staff member was unable to provide

appropriate supervision to ensure her safety and this resulted in Kate's mum experiencing another fall, luckily without serious injury. Through this experience, Kate felt saddened that limited supports were available to help her mum have more freedom to stand up and move around and believes it is an area that requires further consideration for other people in this situation.

"It comes down to quality of life and valuing someone and not really seeing that, you know, not seeing that as important that someone with advanced dementia get the support to stand up or just move around a little bit when they want to."

Overall, Kate felt communication was a key issue which significantly influenced the quality of care her mum received whilst living at the residential aged care facility. Kate strongly believes that problems could have been avoided had carers been allowed to inform family about significant medical issues in addition to notifying the registered nurse. She feels gratitude to the carers who occasionally passed on information when an opportunity arose but also feels sad that in doing so they risked disciplinary action from their employer.

In addition, Kate feels that no matter what stage of life a person is at, they deserve to have the opportunity to stay physically active. This opportunity was only provided to Kate's mother as both her and her sister were able to advocate and make it happen.

Danielle's Story

The name has been changed but the experiences are real. This case study focuses on the experience of a woman who was closely involved in the care for her late father who lived in residential aged care for 13 years. Danielle's father moved into residential aged care when he was only 60 years old after having a stroke, leaving him with multiple disabilities. Unable to speak, or provide consent, Danielle was appointed as her father's legal guardian for 12 years. This story is told from Danielle's perspective.

Over the 13 years her father lived in residential aged care, Danielle felt there many times when her father did not receive quality care or was treated with dignity and respect. For example, Danielle lived 7 hours away and frequently travelled the 14-hour round-trip to visit her father. While she advised staff in advance that she was visiting, she would often arrive to find her father unshaven, hungry and sitting in a dirty nappy. Danielle often wondered what happened on the days when staff knew she was not coming to visit. This was one of many examples where Danielle felt her father was not treated with dignity and respect.

Another example was the way staff communicated with her father whilst they were delivering care. To Danielle, it was the little things that made all the difference. For example, when staff came into her father's room, they would introduce themselves, explain why they were there and have a conversation with her father even though they knew he was unable to say anything back. Danielle felt these staff members made all the difference to her father's quality of life and treated him with dignity and respect. However, unfortunately this type of treatment was rare and more often than not staff members would just walk into her father's room without saying a word to either of them and start delivering care to her father. Danielle felt this was very inappropriate and would often initiate conversation starting with 'hi, my name is...' and ask what they were there to do.

One of Danielle's biggest concerns for older people living in residential aged care facilities was that staff members forget that they were once normal people, leading normal lives and contributing to society. It was important to Danielle that her father was still treated like a person, despite being unable to move or communicate with staff in any way. Danielle made a portfolio about her father to help staff meeting him for the first time see that, before he had a stroke, he was a talented artist, a teacher and had strong ties with his Indigenous heritage.

"I put together this whole portfolio for people who were meeting him for the very first time...because when people saw the kind of person he was before he became the person who didn't speak and who didn't move, they just use to look at him in a completely different light. It's that human side where people saw that he was once a normal person too, you know they changed the way they dealt with him."

While the portfolio helped improve the way staff treated her father, Danielle felt there was no consideration for her father's mental health. The lifestyle programs offered to him were not appropriate. For example, her father was right-handed however after having a stroke, he only had limited movement in his left hand. Knowing he used to be a talented artist, staff provided him with acrylic paints and paper to paint on. Unfortunately, Danielle's father was unable to paint

anything as he was unable to move his dominant hand. Danielle felt this would have been insulting to her father, seeing the paint and paper in front of him and not being able to do anything with them. In addition, being 20 years younger than the other residents, many of the lifestyle programs on offer were not suitable but rather catered to the older residents. Danielle feels her father's needs were not considered, nor was his Indigenous heritage recognised, often leaving him with nothing to do.

"...he was a contributing member of society and then he goes into a nursing home where people don't even recognise his Indigenous heritage. It must have been really soul destroying for him..."

As her father's legal guardian, Danielle would have to provide consent on behalf of her father. As a result, it was important to Danielle that she was kept informed. There were times when Danielle was involved in making decisions about her father's care. For example, her father's doctor always contacted Danielle to discuss treatment options for her father. Together, they would discuss different strategies, including what the doctor would try first, and if that wasn't successful, what the second option would be. Danielle felt confident with this approach and allowed her to provide informed consent on behalf of her father.

However, there were multiple occasions when Danielle was not involved in making decisions about her father's care or provided consent for treatment. For example, her father was given psychotropic drugs in attempt to control his behavior.

"I can't tell you the number of times I went there, and he was sitting there keeled over dribbling in his wheelchair because they had wiped him out with drugs until I intervened."

Danielle feels this was largely because her father was encountering new staff almost every day who were unaware of his complex care needs. As a result, when staff did something to her father that caused him pain, his only way to communicate that to staff was perceived as him being aggressive. Danielle feels this could have been avoided had her father received continuity of care, allowing staff to become familiar with his care needs, recognise his body language, and realise when he was experiencing pain. Unfortunately, this was rarely the case and he was incorrectly perceived by staff as an aggressive person.

"...it is a revolving door of staff and casual...they never seemed to be able to keep people for more than five minutes."

Danielle worked with staff at the residential aged care facility to put a behavior management strategy in place. This involved two levels of intervention, and if both had failed, staff were to call Danielle and get consent to medicate her father. Despite this, staff continued to medicate Danielle's father against her wishes and without consent. Danielle tried to work with management to remind them of the behavior management plan, however this also became challenging with the high turnover of managers. In the end, Danielle gave up dealing with management and care staff at the residential aged care facility. Instead, she decided to deal directly with her father's doctor – someone she knew well and trusted.

With her father unable to move or communicate, transition of care was a major concern for Danielle. There were multiple occasions when her father was transferred to hospital without any communication between the residential aged care staff and the hospital.

“...he would turn up in emergency at the other end and people would come and talk to him...and he wouldn't be able to advocate for himself to tell them what was wrong...they would just have to figure it out.”

Danielle felt this was completely unacceptable and frustrated that she would be left to call the hospital to advise them of her father's multiple disabilities and complex care needs.

In hope of improving the care her father was receiving, Danielle made multiple complaints to the residential aged care facility, and a complaint through the Aged Care Complaints Commission. Each time, Danielle received acknowledgement of her complaint and promises for change. This was often followed by meetings with management, leaving Danielle feeling positive that improvements would be made. However, her complaints never translated into any changes, leaving Danielle feeling frustrated and helpless.

“...it doesn't translate to the people on the ground...whatever they said in an office was not what you saw happening for him.”

Overall, Danielle felt that over the 13 years her father was in residential aged care, there was a decline in the quality of care he received. Danielle believes this was largely influenced by high staff turnover, leaving her father often encountering new staff who did not understand his care needs or the kind of person he was. One aspect that was really important to Danielle was being involved in decision-making for her father's care. Her father's doctor was always very inclusive and ensured Danielle was aware of the different treatment options available, allowing her to provide informed consent as her father's legal guardian. On the other hand, staff at the residential aged care facility often did not seek consent from Danielle, leaving her feeling concerned and ignored. Danielle felt one of the most important aspects of care was treating residents as the people they once were and still are.

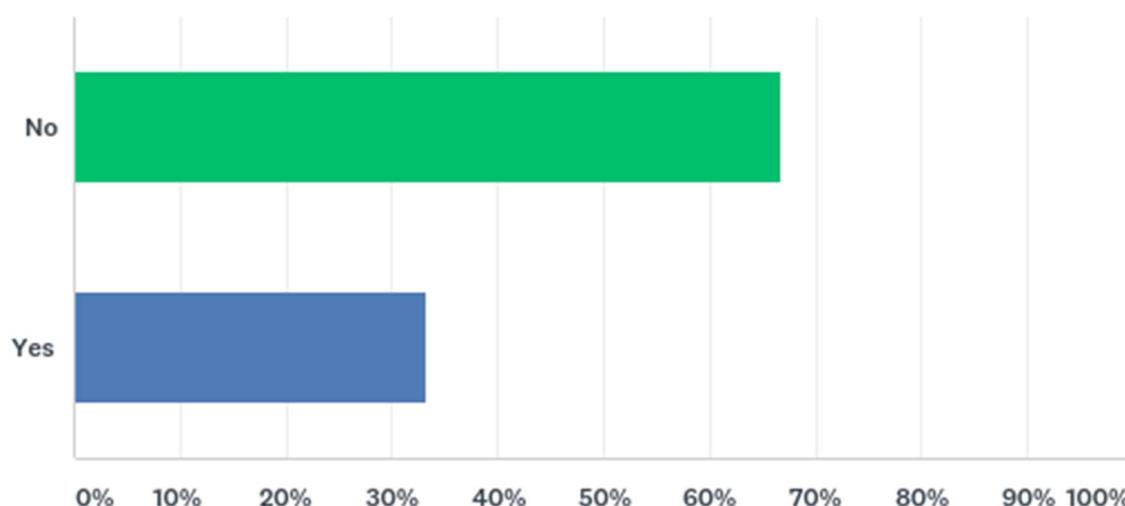
Appendix 2: Survey Results

Our submission to the Royal Commission into Aged Care Quality and Safety (Royal Commission) has been informed by consumer views and lived experiences collected through a survey and telephone interviews. This section covers the key findings of the survey.

CHF developed the survey and interview questions with guidance from the Royal Commission's [Terms of Reference](#) and by the Aged Care Quality and Safety Standards³⁴. The survey was promoted throughout our intensive networks, including HealthUpdate, Consumers Shaping Health, Special Interest Groups, and Social Media. CHF also contacted relevant organisational members via email to request assistance in promoting our survey throughout their extensive networks. The survey remained open for two months.

CHF received a total of 117 responses to our survey. Carers and /or family members represented 63% of responses, while 11% of respondents were from people currently receiving aged care services. The remaining 26% selected 'other' and identified as aged care workers, volunteers, consumer advocates, nurses and potential future consumers of aged care services. The majority of respondents (61%) responded to the survey questions based on their experience in residential aged care, while 39% responded based on their experience in home / community aged care services.

Do you feel confident you (or someone you know) are receiving (or received) care that is safe and right for you (or them)? Please explain why or why not.



³⁴ Aged Care Quality and Safety Commission 2018, *Guidance and Resources for Providers to support the Aged Care Quality Standards*.

A total of 88 people responded to this question and were asked to select one option. The majority of respondents (67%) felt they (or someone they knew) were **not** getting care that was safe and right for them (or someone they knew) while 33% felt they were.

Respondents were given the opportunity to provide further explanation (84). The most common concern highlighted by respondents who **did not feel confident** they (or someone they know) received care that was safe and right for them, were issues relating to the **workforce across both residential and home/community aged care services**. Respondents were concerned about **staff shortages and inappropriate staff to patient ratio** often leading to care being rushed. One respondent said:

"So understaffed that it's dangerous for residents, bells go unanswered and time spent with them is rushed"

[Respondent #22, former worker in residential aged care]

Another respondent with the same concern decided to take matters into their own hands in order to make sure their mother was receiving the care she needed:

"...My mother is living with Vascular Dementia (her mind is like that of a toddler). There are not enough Care Staff to provide her care needs therefore we have introduced her own Private Carers who come into the Facility on a daily basis & this extra care is funded by my Parents' Life Savings which will not last"

[Respondent #89, a carer and/or family member – residential aged care]

Respondents were also concerned about the **lack of appropriately trained/qualified staff** caring for people in both residential and home/community aged care services, **particularly in relation to caring for people with Dementia**.

Additional concerns raised in relation the workforce included:

- **Communication** issues (e.g. staff with poor English-speaking skills, lack of knowledge of patient condition, lack of communication with family members/carers)
- **High staff turnover** leading to lack of continuity of care/unfamiliar staff.

Availability of residential and home/community aged care services was another key concern raised by respondents. This included lack of choice and appropriate services (such as lack of respite beds, particularly in rural and remote regions) and long waiting lists. One respondent said:

"Can't get basic services, if you make it to a wait list, they are long and if you don't get in early you end up getting to a point where your option is nursing home"

[Respondent #9, carer and/or family member – home/community aged care services]

While another respondent said:

*"I don't think nursing homes provide adequate care, even the better ones.
They are essentially palliative care for non-palliative patients"*

[Respondent #90, carer and/or family member – residential aged care]

Medication management was also raised as a key reason why respondents **did not feel confident**, they (or someone they knew), received care that was right for them. Family members and carers raised concern that consumers were not receiving sufficient or timely pain medication or were provided with psychotropic medication to manage behavior. One respondent said:

"...My husband's wandering was treated with risperidone - a form of chemical constraint (without consent) - the contrary, my pleas to have him taken off were ignored - it paralyzed him, and he died within months..."

[Respondent #45, carer and/or family member - residential aged care]

Another key concern raised was **lack of patient-centred care**. Some respondents highlighted individual needs were often not met, or even considered. This included the needs of carers and/or family members. Residents at residential aged care facilities experienced limited social interaction and stimulation. One respondent said:

"They are often given inappropriate food that they cannot swallow - programs that they cannot participate in and treated as though they are problematic when they do not conform to expectations"

[Respondent #45, carer and/or family member - residential aged care]

This was a shared concern for many respondents:

"Some staff...believe residents have to fit in with the institutional needs rather than the personal needs of the residents living in their home"

[Respondent #106, carer and/or family member - residential aged care]

Common themes were evident across the 33% who felt **confident** they (or someone they knew) received care that was safe and right for them. These included:

- Individual choice to move into residential aged care, resulting in a sense of independence,
- Family and/or carers providing advocacy on behalf of the consumer when required,
- Regular visits to 'make sure',
- Workforce: highly qualified and trained health professionals/caring staff, regular communication, attentive staff (small residential aged care facility), and
- Patient-centred care, meeting individual needs (physical and emotional) and providing access to a wide range of activities.

One respondent said they felt confident because:

"I can ring or call in to see my case manager at any time - I feel listened to and all my needs are currently met"

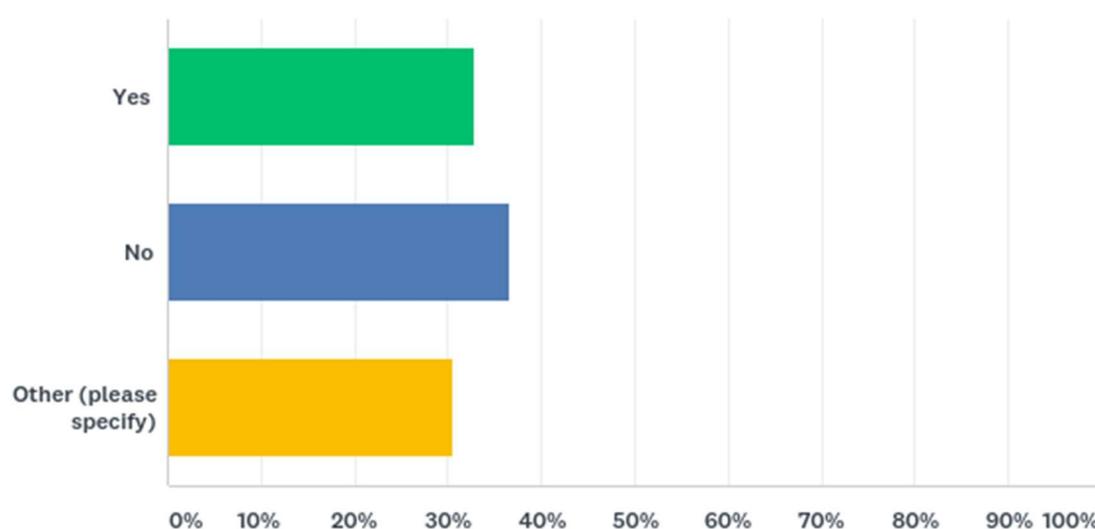
[Respondent #75, a person receiving home/community aged care services]

Another respondent shared the reason for their confidence in the care their Grandmother had received from a not-for-profit residential aged care facility:

"Her choice to move gave her a sense of independence. This was supported fully by the facility she moved in to, and the standard of care she received was nothing short of excellent. At the end of her life she died in her own bed, in her own room in accordance with her wishes..."

[Respondent #4, carer and/or family member - residential aged care]

If the aged care organisation is unable to provide suitable care, do they provide referrals to individuals or other organisations to meet your (or someone you know) health needs?



A total of 83 people responded to this question and were asked to select one option only. Slightly more (36%) respondents felt the organisation did **not** provide appropriate referrals to other organisations or individuals in the event where the aged care organisation were unable to meet a persons' health needs. There were 26 people who selected 'other' and provided further comment with some feeling 'unsure' or suggesting this only occurred sometimes and 'depended on the staff'. Furthermore, other respondents who said that while referrals to appropriate care were made, the care provided was not adequate. One respondent said:

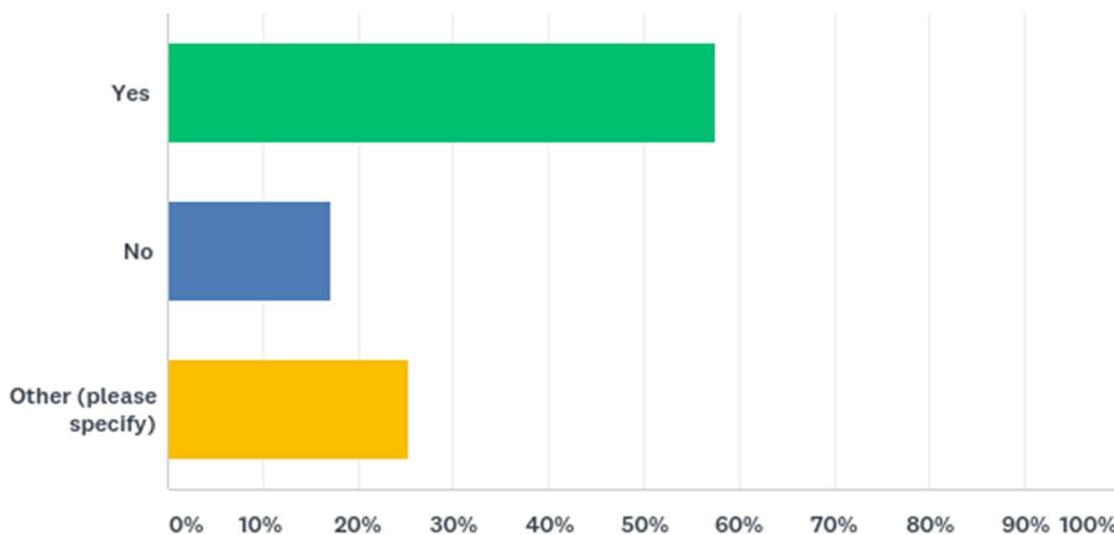
"They did refer to palliative care – however this too was very limited. I don't think the staff of the RAC received the amount of support they should have to be able to look after my mother's needs".

[Respondent #55, carer and/or family member - residential aged care]

Other concerns raised included:

- Referrals provided however long waiting lists or care not provided as frequently as required to meet the needs of the person,
- Lack of time to complete / send referrals,
- Lack of respect for personal choice (e.g. personal preference to see a naturopath), and
- Referrals only made as a result of carers and/or family advocating on behalf of the person receiving aged care services (both residential and home care settings).

Do you (or someone you know) have access to a GP or a Specialist of your choice when required?



A total of 88 people responded to this question and were asked to select one option only. The majority of respondents (57%) felt they **did** have access to a GP or specialist of their choice when required, while only 17% felt they **did not**. There were 22 people who selected 'other' and provided additional comments, with most respondents suggesting it 'varied'. Many respondents felt that while they had access to the GP that regularly visited the residential aged care facility, this was not their GP of choice. One respondent said:

"In rural communities it is impossible to have choice and so older people have to adapt to getting on with someone they may not trust of like"

[Respondent #106, carer and/or family member - residential aged care]

This was the reality for many respondents who highlighted they were unhappy with the GP they had access to through the aged care organisation. Other respondents highlighted they felt they were only able to access a GP or specialist of their choice if they had someone advocating on their behalf or arranged transport privately.

While in relation to accessing a specialist, distance and affordability were highlighted as barriers, and choice remained that of the referring GP.

One respondent said:

“Specialist care is usually 400km away and choice is not yours but the GP’s”

[Respondent #98, carer and/or family member - community aged care services]

How does this make you feel?

A total of 82 people responded to this open-ended question. Respondents who had choice felt more positive compared to those who did not have a choice of the GP or specialist they (or someone they knew) had access to. For example, those who felt they (or someone they know) had access to a GP or specialist of their choice when required, described feeling:

- safe
- confident
- comfortable
- secure
- satisfied
- supported
- empowered
- well informed
- in control
- grateful
- happy

One respondent said:

*“Very satisfied that my family member was being looked after in **accordance with her wishes**, and receiving high quality and respectful care”*

[Respondent #4, carer and/or family member - residential aged care]

And another respondent said:

“Comfortable as my complex needs are known. Not having to remember what has happened in the past which affects my presents because Team Val is on the ball for my best quality of life”.

[Respondent #75, a person who receives home/community aged care services]

On the other hand, those who **did not** feel they (or someone they know) had access to a GP or specialist of their choice when required, report feeling:

- frustrated
- sad
- powerless
- fearful
- annoyed
- a burden
- vulnerable

- inadequate
- depressed
- helpless
- confused
- angry
- awful
- invisible

One respondent said:

*“As a daughter, I have **no power** at all. The doctor will not come unless the nursing home wants it. At times, it has been **impossible to convince** the nursing home that a doctor’s visit is needed”*

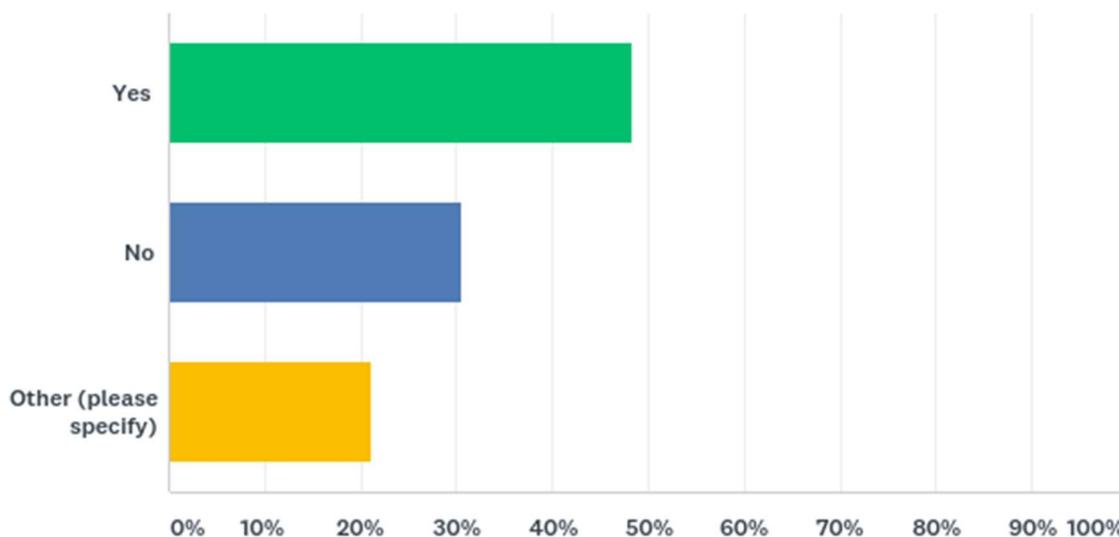
[Respondent #1, carer and/or family member - residential aged care]

Another respondent said:

“I was frustrated watching staff treat residents like inmates. Independence should be encouraged, and assistance provided for individuals to contact their choice of service”

[Respondent #47, former aged care worker - residential aged care]

Do you feel confident, that when the time comes, you (or someone you know) will be given support to make an end-of-life care plan?



A total of 86 people responded to this question. The majority of respondents (48%) felt confident that when the time comes, they (or someone they know) will be supported to make an end-of-life care plan, while 30% **did not** feel confident. 22% of respondents selected ‘other’ and provided additional comments.

Some respondents stated they already had an end-of-life care plan in place, however, do not have confidence that the right people will have access to it when the time comes. For example, one respondent said:

"I feel able to make such a care plan but do not believe that health care workers (e.g. Ambulance staff, doctors or nurses) will access it when needed. I have personal experience of occasions where an Advance Care Directive existed but was not noted, referred to or consulted"

[Respondent #40, carer and/or family member - residential aged care]

Even with an end-of-life care plan in place, one respondent still experienced uncertainty and confusion:

"I made a care plan for my mother but when it came to end of life there were things I didn't really understand and questions unanswered or unprepared for than I expected"

[Respondent #56, carer and/or family member - residential aged care]

Other respondents who were working on developing an end-of-life care plan lacked confidence in the capacity of aged care facilities to provide support. Some were seeking assistance from their GP, or seeking information online, while others were unaware of what support was available to them or what they should do.

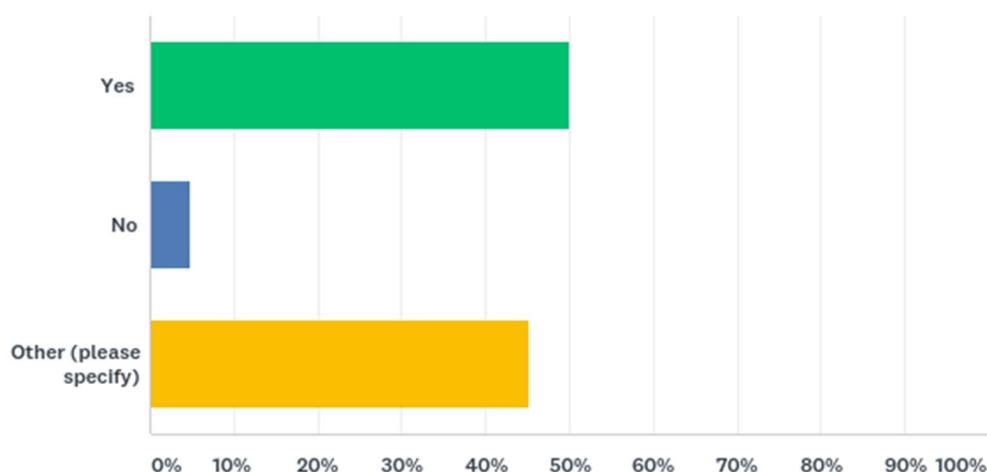
One respondent said:

"Yes, because as a health worker I have ensured that Advanced Care Directives are in place, but many other people do not even know what this is!"

[Respondent #112, carer and/or family member - community aged care services]

Other respondents also emphasised the need for more support for consumers to develop an end-of-life care plan, or advanced care directive to ensure it is both reflective of the persons priorities and can be used by the health system.

Do you feel staff members are kind and caring towards you (or someone you know) when they deliver your care and/or services?



A total of 85 people responded to this question. Almost half of those who responded felt staff were kind, while only 5% select 'no'. The other half of respondents selected 'other' and provided additional comments. Respondents suggested it happened 'sometimes' and 'depended on the individual'. For example, some respondents felt permanent staff were generally kinder and more experienced, while agency staff or casual staff were less empathetic towards elderly people and were less likely to have the 'right personality or training' suitable for the job.

Respondents highlighted **lack of time and lack of staff** as the key issues influencing staff behavior towards consumers when delivering care. One respondent said:

"The ones who are kind and caring cannot provide proper care as they do not have time to do so due to lack of staff numbers and qualified staff"

[Respondent #105, carer and/or family member - residential aged care]

While another respondent said:

"Some staff are very caring but get into trouble for focusing on individual needs"

[Respondent #113, former carer]

Some respondents felt staff were kind and caring more often than not, while others felt it was rare to have kind and caring people looking after their family members. One respondent said:

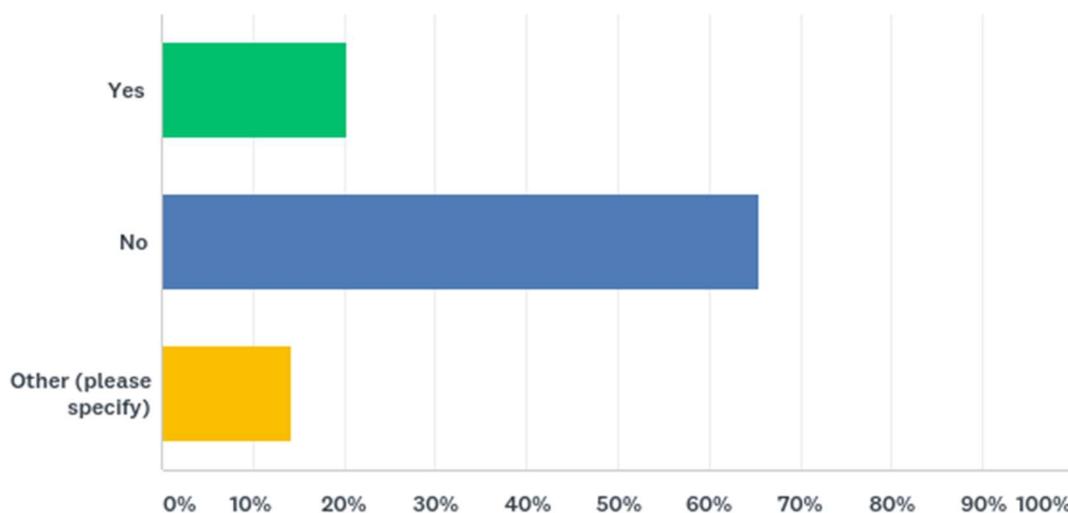
"In my 13-year experience... More often than not, the people looking after your parent are not particularly kind and tend to treat all their patients as inconveniences, rather than elderly (or in some case not elderly) people who deserve respect and compassion and also happen to reside in their facility - which to them is their home. I have witnessed appalling events in the facility"

my father was in over many years. From arrogance when an injured patient was on the floor calling for help and being veritably ignored by all nursing staff. I have seen elderly gentlemen with mobility issues left unattended on toilets stark naked and viewable from public areas”

[Respondent #15, carer and/or family member - residential aged care]

In addition, respondents found care was rushed, and staff were often unaware of individual needs and care plans.

Do you feel staff have enough time to deliver your (or someone you know) care and services?



A total of 85 people responded to this question. The majority of respondents (65%) felt staff **did not have enough time to deliver care and services** to them (or someone they knew), while only 20% felt staff did have enough time. 15% of respondents selected 'other' and provided additional comments. Some respondents felt this varied between facility however staff shortages (particularly on weekends), lack of training, and lack of flexibility appeared to be a common reason. While one respondent felt staff appeared to be organized and had enough staff.

How does this impact the quality of care and/or services you (or someone you know) receive?

A total of 78 people responded to this open-ended question. The majority of respondents felt staff **did not** have enough time and described care as 'rushed', 'non-individualised', 'unsafe', 'inadequate', 'dangerous', and 'frightening'. In addition, respondents highlighted call bells are often left unanswered, quality of care is reduced, corners are cut and there is often no time to build trusting relationships leaving residents 'confused' and 'anxious', particularly for people with dementia. Furthermore, some respondent highlighted personal choice and preferences are often not taken into consideration and some were left feeling 'worthless', 'a burden' and 'uncared for'.

One respondent said:

"It impacts every single aspect of their care. It is terribly distressing to see your parent fed meals at a faster rate than they can possibly chew or safely swallow their food because the staff member has to feed 5 other people...No person in an Aged Care facility should ever be made to rush so as to fit with someone else's convenience. They are residents, for all intent and purposes in a HOME that should care for them with compassion and respect".

[Respondent #15, carer and/or family member – residential aged care]

While another respondent said:

"At best: sub-standard care with no time for compassion or attendance to quality of life. Poor food, people left for extended periods of time sitting in a chair, not taken for a walk or put back to bed, not taken outside to get some fresh air and sunshine and 'enjoy' the day, not taken to the toilet regularly. At worst: sub-standard care leading to malnutrition, pressure ulcers, unrelieved pain, infection and untimely death."

[Respondent #114, carer and/or family member – residential aged care]

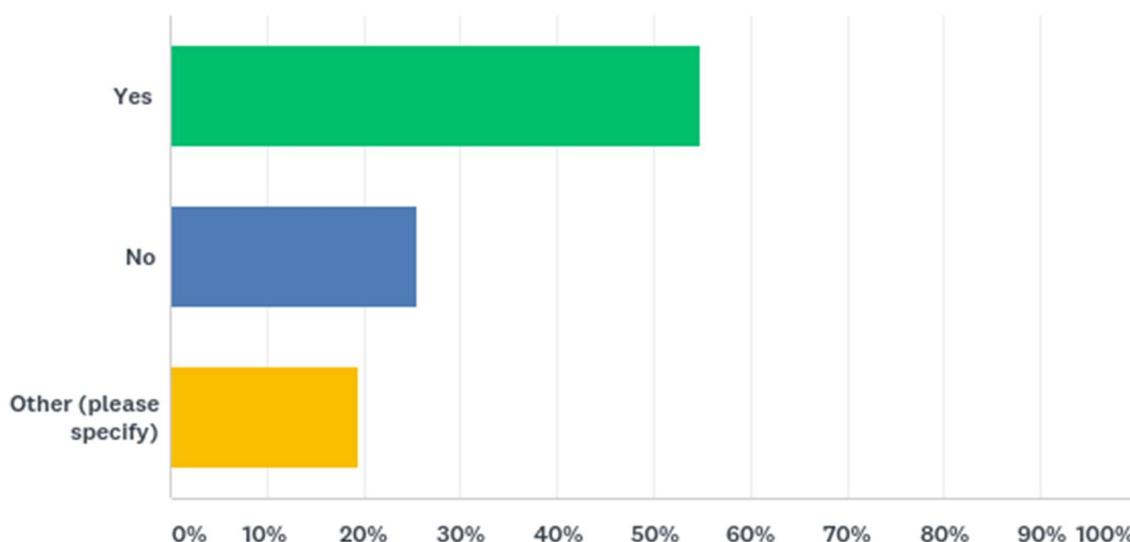
Rushed care was not unique to those in residential aged care but was also a common experience for those receiving community/home aged care services. One respondent described how it impacts their care:

"Creates stress and I feel on edge because I'm a nuisance if I hold up my care worker and make them late for the next client – some services have no idea how long it takes to drive a country road safely as compared to a main road."

[Respondent #75, a person receiving community aged care services]

There were only a couple respondents to this question who felt staff **did** have enough time described the care as 'respectful'.

Do you (or someone you know) often receive care and/or services from the same staff?



A total of 83 people responded to this question, with the majority of respondents (54%) selecting 'yes', they often received care and/or services from the same staff, and only 25% feeling that did not. 21% of respondent's selecting 'other' and provided additional comments. Most of those who provided additional comments felt there was often two or three regular staff members however the majority were casual, or agency staff making it difficult to develop trust and provide continuity of care to consumers. One respondent said:

"Sometimes you could be lucky to have the same person for a while and other times it is a new face every week"

[Respondent #, carer and/or family - community aged care services]

One respondent shared the high-turnover of staff impacted the quality of care her father received in residential aged care:

"Over a 13-year period I also witnessed the revolving door of staff in the facility concerned. A very small cohort of people (3) were there for the duration of my father's residence, but everyone else were simply revolving resources. For people like my father this presented a difficult problem because his multiple disabilities meant he could not communicate verbally and so having an experience and understanding of his nonverbal cues and communication was very important to his comfort and his wellbeing. A revolving door of carers was unhelpful and fueled significant behavior issues for him"

[Respondent #15, carer and/or family member - residential aged care]

How does this make you feel?

A total of 76 people responded to this open-ended question. Those who often received care and/or services from the same staff member described feeling:

- confident
- comfortable
- valued
- pleased
- supported
- secure
- at ease

Many of these respondents highlighted they felt confident and comfortable because they (or someone they know) got to know the staff member, develop trust and the staff were able to recognise and respond to individual needs, including changes in a residents behaviour or health. One respondent described their carer as 'family', while another respondent said they felt:

"Confident that parents feel comfortable with that person in their home. And the worker gets used to their routine"

[Respondent #115, carer and/or family member - community aged care services]

While another respondent highlighted consistency helped their mum feel at ease. The respondent said:

"Great, mum had anxiety a lot so having the same people was a big factor in her care"

[Respondent #56, carer and/or family - residential aged care]

Those who **did not** often receive care and/or services from the same staff member felt:

- upset
- sad
- uneasy
- concerned
- frightened
- uncertain
- frustrated
- confused
- anxious
- fearful
- irritated
- inadequate
- residents 'tasks' not people

One respondent suggested it was 'almost not worth having a care worker' as both her and her husband had to get to know new people frequently. This was a common frustration. Another respondent said:

"Upset that my mother has to get use to a new person coming into the home as she feels embarrassed about her circumstances."

[Respondent #112, carer and/or family member – community aged care services]

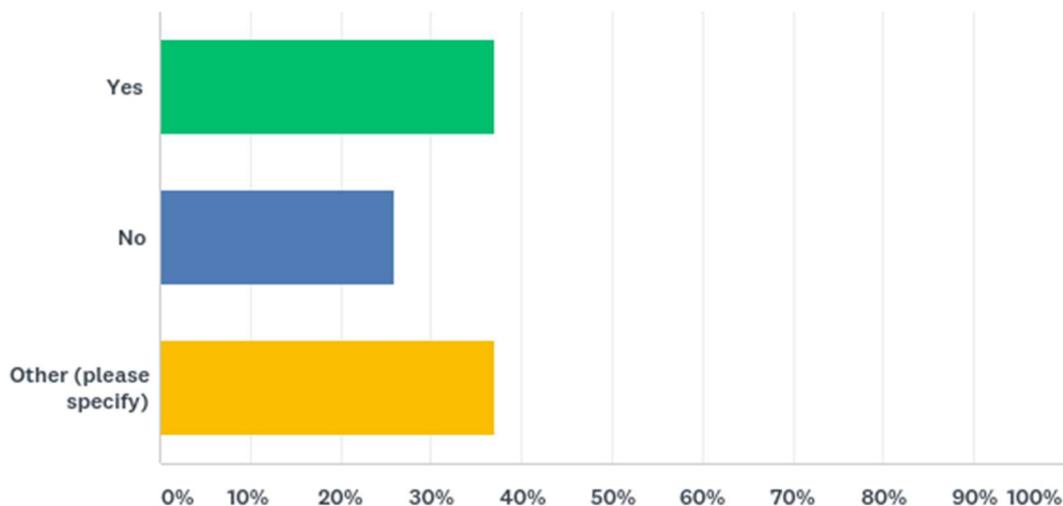
Many of these respondents preferred consistency and felt it improved the delivery of patient-centred care and allow staff to recognise individual needs. While some respondents highlighted consistency was only positive if they (or someone they knew) felt comfortable with the staff member providing care and/or services. One respondent said:

"My husband felt good when the staff he trusted were rostered on. When relief or agency staff were working, he suffered in silence"

[Respondent #67, carer and/or family member - residential aged care]

It was suggested by some respondents that residents should have more choices of which staff members care for them. Respondents also highlighted that frequent change can be unsettling for the elderly as they often do not like change.

Overall, do you feel that your (or some you know) medication is managed well through the aged care service?



A total of 82 people responded to this question. 37% of respondents felt medication **was managed well** through the aged care service, while **26% did not**. 37% of respondents selected 'other' and provided additional comments. Generally, people felt their (or someone they know) medication was managed well 'sometimes' or 'most of the time'. There were however concerns raised about the frequency of medication reviews, with many people suggesting they did not happen enough. In addition, some people expressed frustration that they had to initiate a medication review to make it happen. On the other hand, one respondent had weekly reviews with their GP, while others had their medication reviewed by their pharmacist and managed using Webster Packs.

For those in residential aged care, some suggested 'medication is used to solve everything'. One respondent said:

*"I also often discovered my father had been prescribed 'new' medications by the odd things that turned up on the pharmacy bill. Given I had full Guardianship of my father I had to inquire on multiple occasions as to what these medications were for, who prescribed them and why. I raised this issue multiple times and eventually made a complaint to the HCC about the practices which included the **administration of scheduled drugs that subdued him to make him more compliant**"*

[Respondent #15, carer and/or family member - residential aged care]

While staff shortages also influenced medication management, particularly in residential aged care. One respondent said:

"...sometimes certain medication should be taken the same time every day, or a certain time before eating. If not enough staff this does cause problems".

[Respondent #11, carer and/or family member - residential aged care]

Were you (or someone you know) provided with information, in a way you could understand, what the medication was for?

A total of 79 people responded to this question. 41% of people felt they (or someone they know) **were** provided with information, in a way they could understand, what the medication was for. The majority highlighted they received this information during care plan meetings, from their GP and/or specialist, registered nurse, and through their pharmacist. One respondent said:

"Yes, the GP always consulted with family regarding all three people I was caring for with help from the facility concerned"

[Respondent #44, former carer of three relatives with dementia - residential aged care]

Some respondents described this as 'positive' and said, 'they felt confident to ask questions about their medication.'

On the other hand, 24% of respondents felt they (or someone they know) **were not** provided with information, in a way they could understand, what the medication was for. One respondent said:

"No, we had to seek information and clarification on a number of occasions"

[Respondent #65, carer and/or family member - residential aged care]

Another respondent said:

"No, but as an RN I can decipher for my mother what the medications are for and when to take them. Medication mapping does not occur, and explanations of side effects are non-existent."

[Respondent #112, carer and/or family member – community aged care services]

The remaining 35% of respondents felt they only received information 'sometimes' and similarly suggested they only found out information when they sought an explanation or if there was a 'good' GP or RN involved. Furthermore, some respondents highlighted they were initially provided with information however changes were often made without consultation or explanation.

One respondent said:

"Not always. More...it's time for your medication, here's some water and the tablets."

[Respondent #67, carer and/or family member – residential aged care]

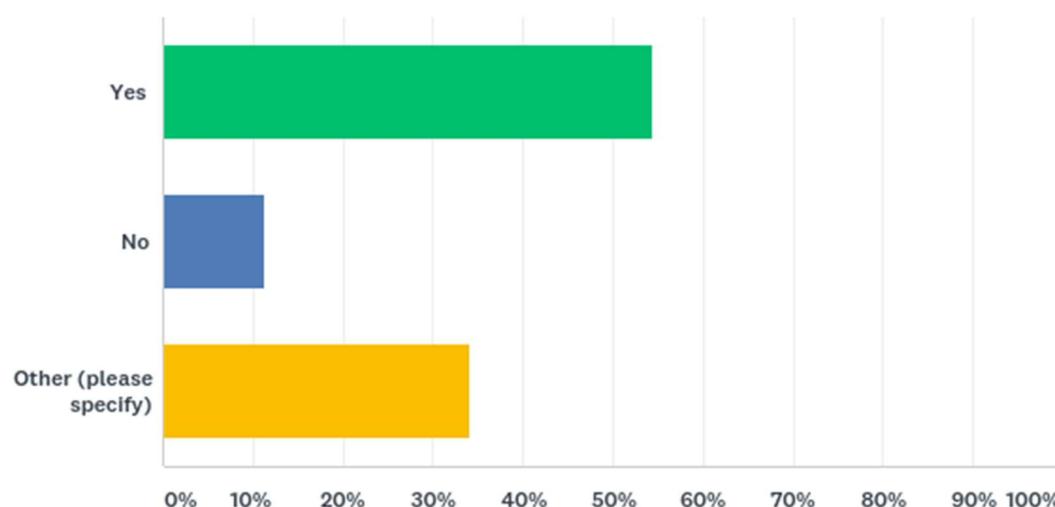
Others took matters into their own hands and researched medication online to gain further understanding. Furthermore, some respondents felt that while they were given some information, it was insufficient to explain the complexity of, or newly prescribed medicines.

One respondent said:

"The complexity of medications requires a lot more explanation than what is given. My mother needed acute pain management – I had to be there and demand for her to get what was needed so she wouldn't cry all night in pain."

[Respondent #44, carer and/or family member – residential aged care]

Were you given the opportunity to ask questions and/or raise any concerns?



A total of 79 people responded to this question. Over half (55%) felt they were given the opportunity to ask questions and/or raise any concerns, while 11% did not. 34% of respondents selected 'other' and provided additional comments. Those who provided additional comment suggested opportunities to ask questions and/or raise concerns were rare and often had to create their own. Some people made appointments with facility managers, while others only received responses to their questions and/or concerns after making several complaints. Some people suggested it was often too difficult as staff were too busy and appointments were not always kept. One respondent said:

"We were, but it was difficult to find the right people, and always had to wait for them to get back to us at their convenience"

[Respondent #94, carer and/or family member - community aged care services]

Others felt that while they had the opportunity to ask questions and/or raise any concerns, they were worried how this might impact their loved one's care. One respondent said:

"Yes, but not without feeling concerned that it will negatively affect your loved one. Plus, they may get defensive and affects relationships in future. This is very difficult to have the courage to raise concerns"

[Respondent #105, carer and/or family member - residential aged care]

How does this make you feel?

A total of 73 people responded to this open-ended question. Those who **were given the opportunity** to ask questions and/or raise any concerns felt:

- confident
- informed

- comforted
- validated
- valued and listened to
- in control
- supported
- at ease
- respected

One respondent said:

"Comforted by knowing the staff were knowledgeable about medications, again this is high quality care"

[Respondent #4, carer and/or family member - residential aged care]

On the other hand, respondents who **were not given the opportunity** to ask questions and/or raise any concerns felt:

- frustrated
- ignored
- concerned
- angry
- upset
- intimidated
- disempowered
- unimportant
- second class citizens
- abandoned
- alone

One respondent said:

"Again, it made us feel as though we were the problem and that we were a nuisance. That we were getting in the way of their work".

[Respondent #94, carer and/or family member - community aged care]